

Heart Valve Voice NICE Consultation Methodology

1. Heart Valve Voice Patient Consultation

Heart Valve Voice carried out an independent and impartial patient consultation on the NICE Draft guideline on heart valve disease presenting in adults. The process was patient-led and inclusive, it would target both treated and non-treated patients. Recognising not all patients want to share their experiences openly we developed a survey monkey to allow more participation.

Requests for participation was sent on all Heart Valve Voice social media channels (over 4,000 members) and many independent valve disease patient Facebook groups (a community of several thousand patients). Interested patients were invited to a HVV Closed Facebook group and we maintained close contact with the independent patient-led Facebook groups.

On the 2nd February 2021 Heart Valve Voice held a patient training session for four patients who were chosen as Ambassadors. We agreed a strategy for responding to the guideline and methods of encouraging participation which included interactive webinars, surveys and interviews.

On the 9th February 2021, The Patient Ambassadors participated in a training session on the NICE guideline and took part in an education session on NICE guideline methodology led by Neil Betteridge, Patient Engagement expert.

In partnership with the Patient Ambassadors, the Heart Valve Voice senior leadership Team and Neil Betteridge developed an interactive webinar and survey monkey investigating patients experience of four key areas of detection, diagnosis, treatment and recovery.

The interactive webinars were carried out on the following dates:
22nd, 23rd, 26th, 28th April

The survey monkey was opened from 21st April until the noon on the 29th April.

2. Engaged Patient Facebook groups included

Bicuspid Aortic Valve (BAV), Heart Valve Surgery Support Group, Warfarin & Support Pre & Post Heart Valve Surgery, Mitral Valve Repair Patients Group, Mitral Valve Replacement Group, UK aortic & heart defects pre surgery / post surgery, UK Aortic Valve Replacement Group

3. All Party Political Group on Heart Valve Disease

Heart Valve Voice is also the secretariat for the All Party Political Group for Heart Valve Disease and facilitated two oral evidence sessions to collate intelligence that could inform a response to the guideline and invited 100 stakeholders to submit written evidence. Chaired by Steve McCabe and facilitated by the Chair of the Heart Valve Voice Clinical Advisory Group Huon Gray the first session was held on the 24th March 2021 and included clinical experts and patient Ambassadors. On the 14th April 2021 a second session as held and included expert opinion from patient advocacy groups and industry representatives through the ABHI.

[A narrative of those session can be held here:](#)